

new directions

...offering
information &
inspiration
to individuals with
disabilities and
their families
as they direct their
own supports and
services



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Editors Note: *This issue of New Directions is dedicated to the memory of Colleen Fraiser. Sixteen years ago, on the eve of the passage of the Family Support Act of 1993, Colleen called on families and advocates to carefully consider how our State's Family Support System would transfer the decision-making power from families to the self-advocates their children would become as young adults. That time has come.*

Finding A Balance Family Support and Self-Directed Services: *Who is REALLY in Charge*

In one approach, the motto is "what ever it takes" and the family is in charge of services. In the other, its all about 'self-direction' and the person with a disability manages services and supports. How can these two service models work together, especially when what the family wants is not what the person with a disability wants? And, how can someone with a significant intellectual disability get 'supported' without getting 'controlled'?

To help get an answer, New Directions turned to John Agosta, Ph.D., Vice-President of Human Services Research Institute of Portland, Oregon. Agosta came to New Jersey recently and spoke to families, providers and self-advocates at a lecture sponsored by the Boggs Center on Developmental Disabilities.

Agosta believes it is important to understand the context in which family support and self-directed services developed. "In recent years, we have seen a growing service demand, greater budget stressors, direct care workforce shortages and a continued push for community participation," he said. "Most people with developmental disabilities live at home with families. It is therefore natural, given the pressures on the system, that new service models would shift more of the financial and planning responsibilities onto families and individuals."

Agosta also sees a reliance on what he calls "legacy systems," - models of service delivery that are no longer state-of-the-art, but still in operation. "The disability service system is a living museum," said Agosta, with each 'specimen' in the museum reflecting the best practices of the era. "Institutions were a good idea in 1850 because there was nothing else," he added. "But they are still around today, and we have added group homes, supervised apartments, sheltered workshops, day habilitation, job coaches, family support and self-directed services. It is the most expensive way to run a system because we have so many different infra-structures, each competing for funding." He argues that these legacy systems have held generations of people 'hostage' in outdated services.

"...The disability service system is like a living museum. We just keep on adding new programs and services to the collection, but generations are held hostage..."

-John Agosta, Ph.D.

continues on page 2

Finding A Balance continued from cover

Family Support took root in the 1980s and recognized that families caring for a child with disabilities at home needed help and support to avoid premature out-of-home placement. It views the family as a whole, with a belief that if the family is supported, it will benefit the person with a disability. Programs in most states make use of structured services, cash assistance and informal, natural supports. Families are viewed as 'experts,' and put in charge of determining what they need and how it is delivered.

Family support and empowerment systems make sense when a child is younger and parents are in charge. But as the person with a disability ages, it is natural that decision-making should shift, giving way to personal empowerment and self-advocacy. At some point, the decision-making may shift entirely or it may remain shared.

According to Agosta, the idea that families are "experts" is flawed. "Just because you happen to have a child with a disability does not make you an expert," he says. This does not mean, however, that families' interest and preference should not be considered and respected. He sees a similar flaw with self-directed services. "Over the years, there have been myths that surrounded people with disabilities," he says. "These myths drive the way in which we provide services." The old myth, according to Agosta, was that people with disabilities could do nothing. But the new myth that has re-

placed it is that people with disabilities can do *anything* if they persevere, try harder or get help. These myths hurt people by failing to honor both their abilities and disabilities. He illustrates his point with a quote from a self-advocate:

"...When it comes to community inclusion, you all talk a good game, but the truth is, it is very hard, and we need more help..."

- self-advocate

"When it comes to community inclusion, you all talk a good game, but the truth is, it is very hard and we need a lot more help."

Agosta sees a central challenge to self-directed services: "Without good help, most people with intellectual disabilities cannot control their own lives. But with too much help, or the wrong type of help, they are no longer in control."

Agosta urges that we find ways to "honor the person's disability" in offering supports. "With good and appropriate supports, people with significant disabilities can exercise personal control and decision-making in ways that matter to them," he said.

Agosta has learned that self-direction means different things to self-advocates than it does to parents and providers. "Most of the self-advocates I have spoken to want to 'live a real life.' They want to control dating and sexuality; house rules, like what they eat for dinner, when they go to bed and what they watch on TV. They also want to make choices about employment and have a greater sense of personal freedom."

Agosta says families and providers worry, and behave in ways that erode freedom and personal control, offering what he calls 'bad help.' What then, is 'good help' and how can it be provided?

The Basic Principles

Family Support

GOAL: Support the family so that the individual with a disability can remain at home.

- Family-centered
- Family-driven
- Family-controlled
- Accessible and Convenient
- Culturally competent
- Available through the developmental phases
- Respectful of family expertise
- Flexible

Self-Determination

GOAL: Provide supports so the person with a disability can live a life of choice in the community.

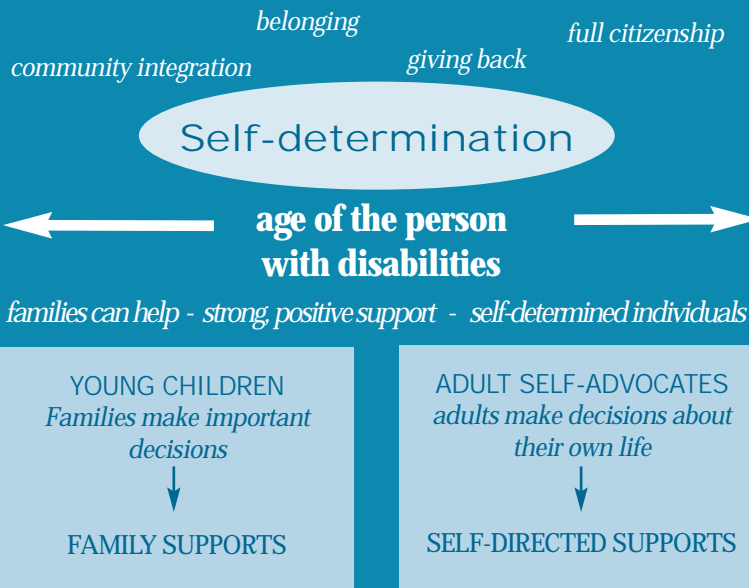
- Consumer-driven
- Freedom to live a meaningful life
- Authority over support budget
- Support to organize resources as wanted
- Responsibility to use public dollars wisely.

Agosta offers the following advice:

1. Place the individual in a meaningful position of power, where his or her opinions and preferences can be taken seriously. A position of power assumes a level of competency to make a decision. Many decisions can be structured in a way that allows the person some level of autonomy. For example, if there is a decision to make about a Saturday afternoon activity and the only option is a movie, ask if the person wants to see movie A, B or C. If the choices are broader, ask if the person wants to go to the movies or to a ballgame. If there is an open-ended option, ask what

continued on page 3

Who directs the Supports?



Consider...

- What is the age of the person?
- What are the person's intellectual disabilities?
- What is the culture of the individual and the family?
- Who REALLY makes the big decisions? A guardian?
- Who really makes the day to day decisions?
- Who directs the actions of support workers and care givers?
- When the case manager or broker calls, who do they answer to?
- What is the 'focus of support'?
- When public money comes into the household, who makes the decisions?

National Center for Family Support, HSRI, John Agosta. Ph.D.

CONTINUED FROM PAGE 2

the person wants to do that afternoon. Decisions of greater significance can be considered similarly and options structured accordingly. He urges not to offer choices if there are none.

2. Listen to the individual. If necessary, include someone else with no vested interest in the outcome of the decision. "Sometimes a third party listener can hear things that neither of you can," advises Agosta.

3. Apply useful assistive technology.

4. Plan for meaningful supports and education to counterbalance the effects of the persons's intellectual disability. Agosta says we often withhold vital information because of our own discomfort, or our assumption that the person 'can't handle it.' In doing so, we set them up to fail. "We may hold back information and opportunities on important parts of life, like sexuality and dating, dealing with rejection, having kids and getting married. Yet these are the very areas in which self-advocates tell us they want to make more choices and have more control." Agosta also urges that we talk openly about death and dying, and grief issues. "Withholding information about illness or the death of a loved one is not going to help the person with a disability," says Agosta. "We need to talk about these things and provide meaningful support."

Agosta urges us to "get our thinking straight" when it comes to the ways in which we provide supports. Family empowerment themes are valid within the

CONTINUES ON PAGE 4

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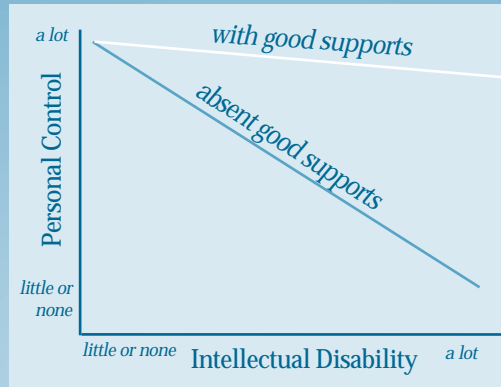
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National Center for Family Support, HSRI, John Agosta, Ph.D.

continued from page 3

context of families when the person with disabilities is young, but personal empowerment and self-advocacy gain validity as the person ages. People with disabilities want an adult role in shaping their personal lives and in shaping policy that affects them. "Let's not offer family support services and call it self-direction," cautions Agosta. "People can tell the difference."

Agosta also advises that we question *all* authority, especially our own. "Inspect what you call things and how you refer to people," he said. "Inspect the true relationship between you and the people you seek to support. Consider who makes the policy decisions and who makes and enforces the rules that govern every day life."

Lastly, Agosta urges that we promote self-advocacy at every level. "Pay attention for opportunities," said Agosta. "Look at the individual level, the household and agency level, and the regional and state level."

Using these strategies, Agosta believes we can provide supports which recognize that a person has a disability, but with the right kinds of supports, can lead a more self-directed "real life."

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